

Fetal Alcohol Spectrum Disorder (FASD), criminal justice and government responses: An evidence brief

The purpose of this brief is to outline evidence about Fetal Alcohol Spectrum Disorder (FASD), its prevalence in the criminal justice system, problems with screening, assessment, support and National Disability Insurance Scheme (NDIS) eligibility. It also focuses on actions that Australian Governments can take to address these issues.

Key points

- There is a high prevalence of FASD in the Criminal Justice System, with no routine screening.
- The Senate inquiry into *Effective approaches to prevention, diagnosis and support for FASD* (Senate FASD Inquiry) Inquiry made recommendations for State and Territory Governments to improve awareness, prevention and support for people with FASD, including screening young people in child protection and youth justice systems.
- FASD diagnosis is complex and expensive and there are limitations on screening and assessment. This leads to inadequate support and services for people with FASD.
- NDIS has gaps in access and eligibility for people with FASD.
- The Australian Government has funded a National Program on alcohol, pregnancy and breastfeeding.

1. Fetal Alcohol Spectrum Disorder (FASD)

Alcohol consumption in pregnancy increases the risk of children being born with FASD.¹ Alcohol passes across the placenta during pregnancy and the fetus has minimal ability to metabolise it due to its size and development. This is why the National Health and Medical Research Council recommends that 'women who are pregnant or planning a pregnancy should not drink alcohol'². Other risks of alcohol consumption in pregnancy include miscarriage, stillbirth, low birth weight and pre-term birth.^{3,4,5}

FASD is a diagnostic term describing a range of neurodevelopmental impairments⁶. It describes impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. People with FASD experience challenges in their daily living and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each person with FASD is unique and has areas of both strengths and challenges.⁷

FASD is the leading preventable developmental disability in Australia. Due to inadequate FASD screening and diagnosis, the prevalence of FASD is not known. However, estimates suggest that FASD affects between two to nine per cent of babies born each year.⁸ Aboriginal and Torres Strait Islander communities are disproportionately affected by FASD, with a rate of up to 12 per cent of births in some remote communities.⁹

Without diagnosis and appropriate intervention, people with FASD have a higher likelihood of secondary issues such as requiring greater education, health and mental health support, problems with parenting and employment, homelessness, and problematic alcohol and other drug use.¹⁰ With the many co-morbid conditions people with FASD experience,¹¹ the medical and social costs are great. In Australia, the annual cost of FASD in 2018 was estimated at \$1.18 billion.¹²

Australia has comparatively high rates of alcohol consumption during pregnancy.¹³ There are a range of factors contributing to this such as wider socio-cultural factors and the social environment around

women who are pregnant, including their own attitudes and beliefs.¹⁴ Research has also shown that levels of alcohol use prior to the pregnancy and experience of intimate partner violence increase the likelihood of women using alcohol during pregnancy.^{15,16}

Other factors include:

- lack of awareness of the National Alcohol Guidelines and lack of awareness of risk,
- just over half (51 percent) of all pregnancies are unplanned,¹⁷
- relatively high levels of alcohol use across the population,¹⁸
- inadequate support and services for people with problematic alcohol use, and
- limited use of screening and brief interventions in antenatal care.

The underlying causes of FASD, therefore, are complex and prevention initiatives require a range of efforts to inform and support women who are pregnant to stop or reduce their alcohol intake. The World Health Organization *Global Strategy to reduce the harmful use of alcohol* acknowledges that whole of population approaches to alcohol policy, targeting the price, promotion and physical availability of alcohol, are the most cost-effective policy approaches to reduce overall population use and alcohol harm, including FASD.¹⁹

2. FASD and the Criminal Justice System

There is a high prevalence of FASD in people detained in the criminal justice system. Research at the Banksia Hill Youth Detention Centre in Western Australia identified that more than a third of the young people screened in detention were diagnosed with FASD. Researchers suggested this may be an underestimate due to, for example, the lack of confirmation of prenatal alcohol exposure, suspecting that almost half of these young people may have FASD.²⁰

People in the criminal justice system are excluded from the National Disability Insurance Scheme (NDIS), Disability Support Pension (DSP), Pharmaceutical Benefits Scheme (PBS) and Medicare. The exclusion of people in prison who have a cognitive disability from essential health and social security supports represents a substantial barrier to people with cognitive and mental health impairments getting adequate support, care and protection for their disability-related complex support needs. Screening, diagnosis and support should be made available for people in the criminal justice system.²¹

3. The Senate FASD Inquiry

The Australian Senate held an inquiry into *Effective approaches to prevention, diagnosis and support for FASD* (Senate FASD Inquiry) from 2019 to 2021. The final report,²² released in March 2021, made 32 recommendations, some of which relate to areas where states and territories could make improvements. The relevant recommendations for State and Territory Governments are:

- **“Recommendation 12.** The committee recommends that the Australian Government fund a National Prevention Strategy to be developed and delivered in collaboration with State and Territory Governments.” (p. 64)
- **“Recommendation 23.** The committee recommends that the Australian Government work with State and Territory Governments to provide all educators with professional development training in the awareness, understanding and management of FASD.” (p. 111)
- **“Recommendation 24.** The committee recommends that the Australian Government work with State and Territory Governments to ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level.” (p. 111)
- **“Recommendation 27.** The committee recommends that the Australian Government, in partnership with State and Territory Governments, develop and trial protocols for screening

children and young people within child protection and youth justice systems for FASD.” (p. 112)

These recommendations demonstrate the need for action across the health, education and criminal justice sectors to better prevent FASD and ensure that people with FASD and their families are supported.

4. FASD screening, assessment and support.

FASD diagnosis is complex and expensive and can be difficult to access. This results in many people missing out on the support that a diagnosis facilitates. Receiving a diagnosis is essential for them to be supported appropriately and take steps to manage their disability to get the most from their lives. Additional resources are needed for screening, assessment, diagnosis and support.

Diagnosis requires a multidisciplinary team to do complex physical and neurodevelopmental assessments. Health professionals participating in a diagnostic assessment for a young person may include Paediatrician, Psychologist, Speech pathologist, Occupational therapist. For an adult, the health professionals involved in the diagnostic process are most likely to include Psychiatrist or physician, Neuro or clinical psychologist, and Mental health worker.

Screening provides an initial assessment that can facilitate referrals to supports and services. Screening pathways through General Practitioners, paediatricians, educators and social service providers should be promoted to ensure children who would benefit from a diagnosis and relevant support are identified as early as possible.

The Senate FASD Inquiry recommended that Governments should ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and students with FASD and suspected FASD, irrespective of IQ level.²³ There is also an urgent and critical need to educate health practitioners as many are not aware of the signs or dismiss FASD prior to proper assessments being undertaken. This can include being misdiagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or other disorders.²⁴

Screening, diagnosis and support should especially include all those in the criminal justice system, but for both children and adults throughout the system. Given the high rates of FASD within youth justice settings, appropriate screening, diagnosis and ongoing support is critical to improving the lives of these children and establishing an ongoing pathway out of the criminal justice system.

5. National Disability Insurance Scheme access and eligibility

The Senate FASD Inquiry²⁵ noted that carers, families and individuals impacted by FASD face multiple barriers with the complex task of assessment, diagnosis and supports. People with FASD are further negatively impacted by issues within the National Disability Insurance Scheme (NDIS), such as gaps in funding and support options and a lack of coordination between the health system and the NDIS.

NDIS funding is available for people with FASD, but the process for accessing these supports is complex and fraught with barriers in relation to the burden of proof for functional impairments.²⁶ Due to this difficulty many people with FASD do not gain NDIS support or gain inadequate NDIS supports.

Another challenge with FASD and the NDIS is, as stated above, that people with FASD detained in the criminal justice system, including children, are excluded from the NDIS (and from DSP, PBS and Medicare). The exclusion of people in prison who have a cognitive disability from the NDIS represents a substantial barrier to people with cognitive and mental health impairments getting adequate support, care and protection for their disability-related complex support needs.²⁷

Government intervention in addressing these gaps is critical as screening and assessment may be the only pathway for some people towards gaining a FASD diagnosis and the needed supports.

6. National Program on alcohol, pregnancy and breastfeeding.

In December the National Health and Medical Research Council (NHMRC) released updated guidelines on alcohol. The *Australian guidelines to reduce health risks from drinking alcohol*²⁸ include “Guideline 3: To prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol”. However, there is low awareness of the Alcohol Guidelines:

- In a study of Australian women aged 18 to 45 years, the majority reported negative attitudes about alcohol in pregnancy, however one in three women did not know that alcohol use in pregnancy could cause adverse impacts²⁹.
- Research of Australian women who were pregnant, planning a pregnancy, or who had recently had a baby found that while women were aware that alcohol consumption during pregnancy was “probably unsafe,” they didn’t have information about the actual risks of alcohol consumption during pregnancy for the developing child^{30, 31} and did not view ‘moderate’ alcohol consumption or having an ‘occasional’ drink as being at odds with messages regarding alcohol abstinence³².

FARE has received funding from the Australian Government Department of Health to develop and deliver the National Program on alcohol, pregnancy and breastfeeding from July 2020 to September 2024. The National Program has four streams: targeting the general public, health professionals, women who are most at risk and Aboriginal and Torres Strait Islander peoples. FARE looks forward to engaging with all State and Territory Governments to support the implementation of the National Program.

References

¹ McLean S & McDougall S (2014) *Fetal alcohol spectrum disorders Current issues in awareness, prevention and intervention*. CFCA Paper No 29. Melbourne, Australia: Child Family Community Australia.

<https://aifs.gov.au/cfca/sites/default/files/publication-documents/cfca-paper29-fasd.pdf>

² NHMRC (2020) *Australian guidelines to reduce health risks from drinking alcohol*.

<https://www.nhmrc.gov.au/health-advice/alcohol>

³ Patra J, Bakker R, Irving H, et al (2011) *Dose–response relationship between alcohol consumption before and during pregnancy and the risks of low birthweight, preterm birth and small for gestational age - a systematic review and meta-analyses*. BJOG: An International Journal of Obstetrics & Gynaecology, 118, 1411-21

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3394156/>

⁴ Albertsen K, Nybo Andersen A, Olsen J & Grønbaek M (2004) *Alcohol Consumption during Pregnancy and the Risk of Preterm Delivery*. *American Journal of Epidemiology*, 159(2), 155–161.

<https://academic.oup.com/aje/article/159/2/155/166563>

⁵ Jaddoe VWV, Bakker R, Hofman A, et al (2007) Moderate Alcohol Consumption During Pregnancy and the Risk of Low Birth Weight and Preterm Birth. The Generation R Study. *Annals of Epidemiology*, 17(10), 834-840.

⁶ Bower C & Elliott EJ (2016) *Australian Guide to the diagnosis of FASD*.

https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf

⁷ CanFASD (2018) *What is FASD?*, Canada FASD Research Network (CanFASD) <https://www.nofasd.org.au/alcohol-and-pregnancy/what-is-fasd/>

⁸ Food Regulation Standing Committee (2018) *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26.

<https://foodregulation.gov.au/internet/fr/publishing.nsf/Content/pregnancy-warnings-alcohol-labels>

⁹ Fitzpatrick JP, Latimer J, Carter M et al (2015) *Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project*. *Paediatrics and Child Health* 51(4), 450-457.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/jpc.12814>

¹⁰ Streissguth AP, Barr HM, Kogan J, & Bookstein FL (1996) *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Final Report to the Centers for Disease Control and Prevention (CDC), Technical Report. No. 96-06. University of Washington.

-
- ¹¹ Popova S, Lange S, Shield K, et al (2016) Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet*, 387(1022), 978-987.
- ¹² Food Regulation Standing Committee (2018) *Decision Regulatory Impact Statement: Pregnancy warning labels on packaged alcoholic beverages*. <https://foodregulation.gov.au/internet/fr/publishing.nsf/Content/pregnancy-warnings-alcohol-labels>
- ¹³ Finlay-Jones A (2018) *Reducing harms related to alcohol use in pregnancy: Policy and practice recommendations*. Deeble Institute for Health Policy Research. <https://ahha.asn.au/publication/health-policy-issue-briefs/deeble-issues-brief-no-28-reducing-harms-related-alcohol-use>
- ¹⁴ Holland K, McCallum K & Blood RW (2015) *Conversations about alcohol and pregnancy*. Canberra: Foundation for Alcohol Research and Education. <https://www.canberra.edu.au/research/faculty-research-centres/nmrc/publications/documents/Conversations-about-alcohol-and-pregnancy.pdf>
- ¹⁵ Skagerström J, Chang G & Nilsen P (2011) *Predictors of Drinking During Pregnancy: A Systematic Review*. *Journal of Women's Health*, 20(6), 901–913. <https://pubmed.ncbi.nlm.nih.gov/21671775/>
- ¹⁶ Hutchinson D, Spry EA, Husin HM, et al (2021) *Longitudinal prediction of periconception alcohol use: a 20-year prospective cohort study across adolescence, young adulthood and pregnancy*, *Addiction*. <https://pubmed.ncbi.nlm.nih.gov/34495562/>
- ¹⁷ Marie Stopes International (2008) *Women, contraception and unplanned pregnancy*. January 2008. <https://www.mariestopes.org.au/wp-content/uploads/Real-Choices-Key-Findings.pdf>
- ¹⁸ Cancer Australia (2018) *Apparent alcohol consumption* <https://ncci.canceraustralia.gov.au/prevention/alcohol-consumption/apparent-alcohol-consumption>
- ¹⁹ World Health Organization (2010) *Global strategy to reduce the harmful use of alcohol*. https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf;jsessionid=D0DFC8022ED81DBC4D14FF2E70D67F12
- ²⁰ Bower C, Watkins RE, Mutch RC, et al (2018) *Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia*. <https://bmjopen.bmj.com/content/bmjopen/8/2/e019605.full.pdf>
- ²¹ Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021.p. 102-105 https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²² Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021. https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²³ Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021.p. 95-102 https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²⁴ Weinberg J (2018) *Fetal Alcohol Syndrome Sometimes Misdiagnosed and Under-Reported due to Stigmas Around Drinking*. Vancouver Coastal Health Research Institute. <https://www.vchri.ca/stories/articles/2018/05/01/fetal-alcohol-syndrome-sometimes-misdiagnosed-and-under-reported-due>
- ²⁵ Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021. https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²⁶ Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021.p. 95-102 https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²⁷ Senate Community Affairs References Committee (2021) *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder Report*, March 2021.p. 102-105 https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024357/toc_pdf/Effectiveapproachestoprevention,diagnosisandsupportforFetalAlcoholSpectrumDisorder.pdf;fileType=application%2Fpdf
- ²⁸ NHMRC (2020) *Australian guidelines to reduce health risks from drinking alcohol*. <https://www.nhmrc.gov.au/health-advice/alcohol>

²⁹ Peadon E, Payne J, Henley N, et al (2010) *Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey*. BMC Public Health, 10, 510.

³⁰ Holland K, McCallum K, & Walton A (2016) *'I'm not clear on what the risk is': women's reflexive negotiations of uncertainty about alcohol during pregnancy*. Health, Risk & Society, 18(1-2), 38-58.

³¹ Jones S, & Telenta J (2012) *What influences Australian women to not drink alcohol during pregnancy?* Australian Journal of Primary Health, 18, 68-73.

³² Holland, K., McCallum, K., & Blood, R. W. (2015). *Conversations about alcohol and pregnancy* (FARE)
<https://apo.org.au/sites/default/files/resource-files/2015-08/apo-nid56585.pdf>